European euthanasia laws: questions of compassion

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For more on **euthanasia in Belgium** see *NEJM* 2009; **361:** 1119–21

For more on **euthanasia in the Netherlands** see Articles *Lancet* 2012; **380:** 908–15

Frank Van Den Bleeken, a Belgian man imprisoned for the past 30 years for murder and rape, was last week granted the right to die by euthanasia rather than live a life of "unbearable suffering" in prison. The decision has raised questions about the extent to which the use of Belgium's euthanasia law, in place since 2002, is straying from its original doctrine.

The law states that a patient can receive euthanasia if they suffer unbearably from an untreatable physical or psychological medical disorder. To be granted, the patient's request should be explicit and repeated. Furthermore, the patient must be of sound mind, at least one other independent physician must have been consulted, and all alternative treatment options must have been offered.

It is regarding this last point that Wim Distelmans (University Hospital Brussels, Brussels, Belgium) does not agree with the decision for Van Den Bleeken. Distelmans, an oncologist and professor of palliative medicine, was central in developing the country's euthanasia laws, and has been Van Den Bleeken's treating physician for the past 2 years after repeated requests from the prisoner to die by euthanasia.

"He certainly suffers, and I have empathy for his suffering", says Distelmans of Van Den Bleeken's struggle with sexual delinquency, "but he has not received all possible treatments". Palliative psychiatric treatment, he says, might have helped him to live a more comfortable life. The treatment is available in neighbouring Netherlands, but despite one Dutch centre agreeing to treat him, Van Den Bleeken has been refused leave for treatment. "So for this reason I do not think his case meets the very stringent criteria of the Belgian euthanasia law", says Distelmans.

Despite the court's decision—taken on the advice of three independent psychiatrists—Distelmans believes that Van Den Bleeken will struggle to find a hospital willing to give him euthanasia.

Distelmans is no stranger to controversy. He was the treating physician and did the procedure for two much-debated cases of euthanasia in Belgium: one of deaf twins who learnt they would soon go blind and another of a transsexual man who had had several sex reassignment surgeries that went badly wrong.

"The international media picks up on these cases, focusing on the blindness or identity crisis without knowing the whole picture", says Distelmans. The failed operations had caused the transsexual man much untreatable physical as well as psychological pain, and the twins, among other disorders, had severe respiratory problems. "Losing their sight was a bridge too far", he says. "But these types of cases are very exceptional—they are not representative of most cases of euthanasia."

Bregje Onwuteaka-Philipsen, a professor of end-of-life research at the VU University Medical Center in Amsterdam, Netherlands, agrees. "Much of the public debate goes into cases on the boundaries of what should or shouldn't be allowed", she says, "but the vast majority of cases are in people with terminal cancer".

In both Belgium and the Netherlands—which was the first country in the world to legalise euthanasia, doing so several months before Belgium—about 80% of all euthanasia procedures are carried out for people with terminal cancer. Luxembourg is the third and only other European country to have legalised euthanasia, having done so in 2009.

Because Luxembourg's legalisation on euthanasia is fairly recent, few data are available for analysis. But for the Netherlands, Onwuteaka-Philipsen explains, data are abundant thanks to the country's long-held liberal stance on the issue and investment into research on end-of-life care. Procedures agreed between the Dutch judiciary and the country's medical association for doctors to report a patient's request for euthanasia have been in place since 1993. If criteria for due care were met, no prosecution would take place for doctors carrying out euthanasia procedures. In 1998 the procedure was modified to include an independent panel consisting of a doctor, a medical ethicist, and a lawyer. It was in this form that the law was enacted in 2002.

"Our data show that the numbers of patients dying by euthanasia has been relatively stable", says Onwuteaka-Philipsen. In 1990, before any regulation, about 2450 deaths (1·9% of all deaths) were by euthanasia or doctor-assisted suicide. In 2010, 8 years after the legalisation was introduced, the total was about 3950 deaths (2·9%). Data from Belgium show an increase from 675 deaths (1·2%) in 1998 to 1025 (1·9%) in 2007.

"One of the concerns people have about euthanasia", Onwuteaka-Philipsen notes, "is that if you start letting doctors end a patient's life when they request it, then they might find it easier to end a patient's life when they don't request it".

AFP/Getty Images

Frank Van Den Bleeken

But her data refute those fears. In 1990, about 1000 deaths (0·8%) were the result of a physician ending a patient's life without their explicit request. In 2010 this number had reduced to about 300 deaths (0·2%). Data from Flanders in Belgium suggest a similar decrease, from 3·2% of all deaths in 1998 to 1·8% in 2007; in patients with cancer the proportions were 5·9% in 1998 and 2·1% in 2007.

In line with these findings, Onwuteaka-Philipsen's unpublished data show that since 1990, about 80% of Dutch physicians would consider carrying out euthanasia. Tellingly, with legalisation of the procedure, the proportion who would consider ending a patient's life without their explicit request has plummeted from about 60% in 1990 to just under 10% in 2010.

Another fear about such legalisation stems from memories of the Nazi's enforced euthanasia programmes, with anti-euthanasia groups touting a so-called slippery slope towards the trivialisation of ending a person's life and the targeting of the most vulnerable populations. However, data from Belgium, the Netherlands, and Luxembourg show this not to be the case.

Stefaan van Gool, a paediatric oncologist at University Hospital Leuven, Leuven, Belgium, has a more nuanced objection to euthanasia. "If a patient thinks they are more of a hindrance than a good for their surroundings", he says, "they might feel community pressure that [euthanasia] is a way they can and should use for getting out. Contrary to what was meant by the law, the freedom to decide on their own death has created pressure for some people".

He acknowledges the overwhelming acceptance among Belgian physicians and the public for euthanasia in adults, but believes that Belgium's decision earlier this year to remove the lower age limit of 18 years for euthanasia was ill-informed.

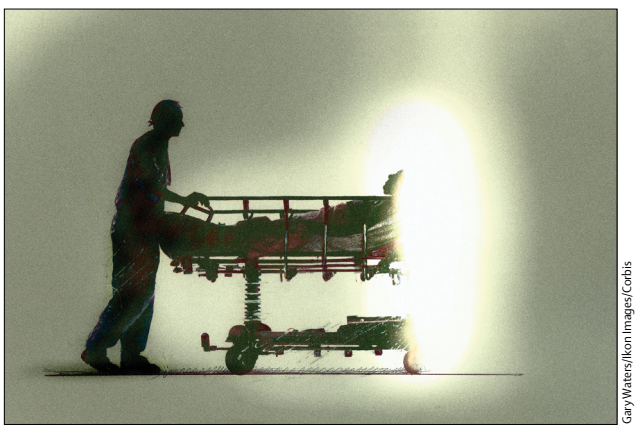
"I've got questions that there aren't answers for and so I believe it was too soon to vote this in", he says, outlining his questions as a lack of objective measures to assess a young person's capacity to make an informed decision, and to rule out the possibility of influence from their parents. Minors, he says, also have poor impulse control compared with adults.

Bernard Dan, a paediatric neurologist at the Hôpital Universitaire des Enfants Reine Fabiola, Brussels, Belgium, was an invited committee member of the Commission on Ethics and End-of-Life of the Belgian Royal Academy of Medicine, which advised in favour of the decision to remove the lower age limit in Belgium. The age limit in the Netherlands has been 12 years since its conception.

"We asked ourselves 'is it fair that age is a major criterion—that if you are unbearably suffering and aged 18 it concerns you, but if you are a day younger it does not?', and the answer was probably not", he explains. "We wanted to insist on this difficult notion of capacity for discernment, whether the individual is able to understand what's going on. But that doesn't imply you can do it at any age—if you have a child of 5 years old the multidisciplinary team are extremely unlikely to evaluate the request favourably."

Belgium is also discussing extension of the law to include people with dementia, but because of the uncertainty around mental capacity for discernment, says Jan Bernheim, a medical oncologist at Free University Brussels, Brussels, Belgium, this discussion has proved too difficult to progress for the time being.

Bernheim, along with Distelmans, led the introduction of palliative care and euthanasia in Belgium. He says that a strong palliative care system is a prerequisite for any country considering legalising euthanasia, and encourages open debate about the extent to which laws should be expanded or contracted. "This discussion has to be out in the open", he says. "It cannot happen, case by case, in the middle of the night between the doctor and the patient."



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Whereas the debate in Belgium centres on the boundaries of the euthanasia law, the discussion elsewhere in Europe is around the legality of assisted suicide, in which the patient is provided with and self-administers a lethal dose. Assisted suicide is legal in Switzerland and discussions to introduce it are ongoing in the UK, France, Spain, and Germany, all wealthy countries with adequate palliative care networks. Italy, says Distelmans, is a long way off because of its Catholic majority.

He sees the discussion about doctor-assisted suicide as encouraging, but discriminatory in nature—it gives the option only to patients capable of administering a lethal dose themselves, leaving those who cannot to suffer. "It's important for oncologists to be involved in these public discussions", he adds. "You can discuss euthanasia theoretically and philosophically, but it's an oncologist who is confronted daily with terrible suffering and knows the difference between treatable and futile suffering. There are many factors involved in a country's decision, but oncologists simply must be involved in the debate."

Dara Mohammadi

For **trends in Flanders, Belgium,** see *Med Decis Making* 2011; **3:** 500–10

For further discussion of **the decision to remove the lower age limit and data refuting the slippery-slope hypothesis** see **Comment** *Lancet* 2014; **383:** 671–72